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14. ABSTRACT The primary aim of this study was to test a theoretically derived predictive model of adolescent functioning to maternal breast cancer. Standardized questionnaires with well established validity and reliability were used to measure 6 theoretical concepts in the model and were obtained from 222 study participants, including mothers recently diagnosed with breast cancer, their spouse, and their adolescent child. Results from tests of the theoretical model revealed that the adolescent was deleteriously impacted under 2 conditions: when the mother's mood was more depressive or when there was heightened tension between the parents. Both heightened marital tension and maternal depressed mood deleteriously affected adolescents' self-esteem. However, the quality of parenting was a protective factor that significantly improved children's self-esteem as well as enhanced their behavioral-emotional functioning. Results argue for programs and services to help both the ill and non-ill parent sustain quality parenting of the adolescent during the first year of diagnosis, treatment, and early recovery from the mother's breast cancer.					
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## **Introduction**

In 2007, an estimated 178,480 women in the United States will be newly diagnosed with invasive breast cancer and an additional 62,030 women will have in situ disease (ACS, 2007). Approximately 22-25% of these women will have an adolescent child, yielding an estimated 52,912-60,127 adolescents. This number does not even consider the thousands of other adolescents impacted by other types of parental cancers, such as lymphoma, leukemia, and lung cancer. To date there has been extremely limited research on the adolescent's adjustment to parental cancer, limited studies on the issues parents face when trying to assist the adolescent, and virtually no rigorously evaluated interventions for enhancing adolescent adjustment (Elmberger et al, 2000; Davey et al, 2003; Hilton & Gustavson, 2002). This means that interventions to help both the adolescent or the parent have little empirical basis in the nursing, medical, or social or behavioral sciences (Lewis et al., 2000; Lewis, 1998, 2004; Rauch & Muriel, 2003; Foley, Back, Coyle et al, 2005). Neither clinicians nor scientists have sufficient data on which to develop and test interventions to assist adolescents who are impacted by maternal breast cancer.

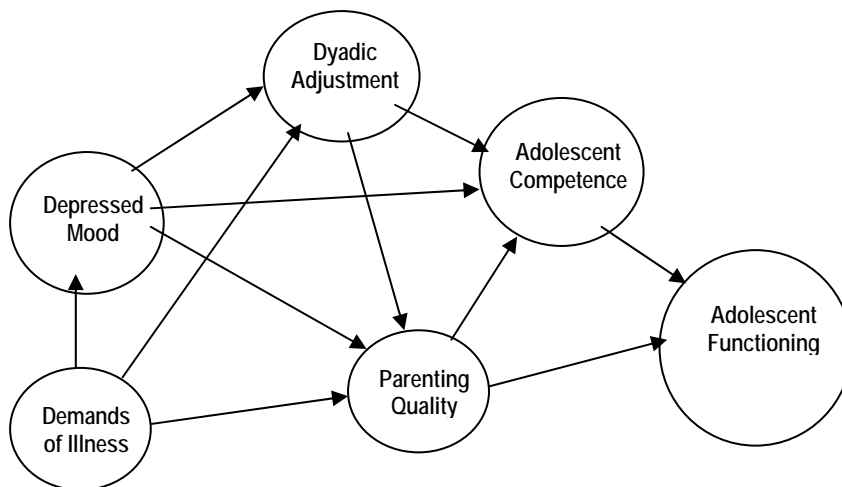
Chronic medical illness in a parent, including cancer, has been studied primarily from the perspective of the diagnosed parent, not the child (Hilton, 1989, 1993, 1996; Hilton & Elfert, 1996; Lewis, 1996, 1997; Lewis & Bloom, 1979). Even when the window of observation into the family's experience with cancer has been expanded to include caregivers (Northouse 1988, 1992; Northouse & Peters-Golden, 1993; Northouse & Swain, 1987; Sabo, Brown, & Smith, 1986; Zahlis & Shands, 1991, 1993), there has been limited documentation of the adolescent's functioning with and adjustment to parental cancer (Lewis, 1986, 1990, 1997, 2004). The reality is that the adolescent children of parents with cancer have been treated with benign neglect except by a small number of investigators (Lewis, 1993, 1996, 1997; Compas et al., 1994; Wellisch et al., 1991, 1992; Welch, Wadsworth, & Compas, 1996).

Results from studies of adolescents whose mothers were diagnosed with breast cancer revealed heightened tension in the parent subsystem [Spanier Dyadic Adjustment] that was generated or exacerbated by the illness (Lewis & Hammond, 1996; Lewis et al., 1989). This heightened marital tension resulted in less effective coping behavior, poorer adjustment in the child, and diminished overall functioning of the household (Lewis, et al., 1989; Lewis & Hammond, 1992). Except for completed studies by the current study team, no other team has examined parental cancer and adolescent functioning within a larger family systems framework. At best, some studies included data from both the adolescent and parent but did not test the association between these data (Barnes et al., 2002; Lichtman et al., 1984; Sears & Sheppard, 2004).

## **BODY**

The primary aim of this study was to test a theoretically derived predictive model of adolescent functioning to recently diagnosed early stage maternal breast cancer. The theoretical model is summarized in Figure 1 below; the explanation that follows moves from left to right in the model. The fathers' and mothers' reported illness demands (Demands of Illness) negatively impact the parent's mood (Depressed Mood). More demands would be expected to result in higher depressed mood. Both parental depressed mood and their reported illness demands negatively impinge on their marriage, negatively affecting their marital adjustment (Dyadic Adjustment). Maladjustment in the marriage, in turn, negatively affects the quality of the mothers' and fathers' parenting behavior as well as adversely affects the adolescent's self-esteem (Adolescent Competence). Diminished adolescent self-esteem and poorer parenting quality deleteriously affect the adolescent's adjustment to the mother's breast cancer (Adolescent Functioning).

**Figure 1: Theoretical Predictive Model of Adolescent Functioning with Maternal Breast Cancer**



## **Methods**

The current study is a secondary analysis of baseline data that were previously obtained from families whose mother was diagnosed with non-metastatic breast cancer. Study participants were recruited from multiple sites in two states in the Pacific Northwest and were recruited from medical providers, including surgeons, radiation oncologists, and hematology-oncologists practicing in within a university setting, private practice, or health maintenance organization. Participants were eligible if the mother was diagnosed within 11 months with *in situ*, regional, or local breast cancer [early stage]; spoke, read, and wrote English among their languages of choice; had an adolescent living at home; and lived within 100 miles of the study

center in each state. Prior to obtaining baseline data, study participants gave written informed consent, including adolescents.

### **Description of Study Sample**

The study sample consisted of 222 study participants who lived in 74 households, each of which included a diagnosed mother, father and adolescent child. Mothers were on average 44 years old (SD 4.4) and had 14.8 (SD 1.74) years of education. Fathers were slightly older, averaging 46 (SD 6.2) years and had 15.4 (SD 2.5) years of education. Time in the relationship ranged from 3 to 31 years, with an average of 19.1 (SD 7.1) years. More than half (53.6%) of the study sample had a family income of equal to or greater than \$60,000. The majority of the families were Caucasian (more than 90%) and 75% of the mothers and 93% of the fathers worked full or part time.

The time since diagnosis ranged from 1 to 11 months, with an average of 5 (SD 2.7) months. The majority (67%) were diagnosed 6 or fewer months. The majority of diagnosed mothers (65%) were surgically treated with mastectomies; 34% had lumpectomies. Most of the mothers (78.4%) were on active treatment for their cancer at the time data were obtained for the current study. The majority of diagnosed mothers (80.8%) reported they had side effects from radiation or chemotherapy and 50% of the mothers were taking medications to manage those side effects.

The adolescent children in the study sample averaged 15.7 (SD 1.8) years, 58% of whom were male. The average number of children in the home was 2.1 (SD .88), ranging from 1 to 5 children in the home.

### **Description of Study Measures**

The 6 concepts in the theoretical model [Figure 1] were measured by standardized questionnaires, each of which is described below.

**Depressed mood** of both mothers and fathers was measured by the total score on the Centers for Epidemiological Studies-Depression scale (CES-D). Prior research has shown the CES-D to be highly related to an increase in illness related demands, as well as a decrease in marital satisfaction and adjustment, along with lower levels of coping and functioning in women diagnosed with illnesses including fibrocystic breast disease, diabetes or breast cancer (Lewis et al., 1989) Alpha internal reliability coefficients are 0.88 and 0.87 respectively for the mothers and fathers CES-D.

**Dyadic Adjustment** for both mothers and fathers was measured by the Spanier Dyadic Adjustment total scale score. The DAS is a 32-item self-report scale which assesses the marital quality and relationship of the couple. The total DAS scale score encompasses several dimensions including partner consensus, satisfaction, expressing affection and cohesion. Internal reliability coefficients are 0.92 and 0.91 respectively for mothers and fathers for the study sample.

**Demands of Illness** are the reported illness-related concerns that the parent attributes to the diagnosed mothers' breast cancer and are measured by the Demands of Illness (DOI) Scale.

The total scale and 7 subscales measure how the demands of the breast cancer affect the lives of the family members. Subscales include illness demands affect on physical symptoms, personal meaning, family functioning, social relations, self-image, symptoms monitoring, and treatment issues. Prior testing of this scale found a direct association with depressed mood for spouses of long termed illness women (Lewis et al., 1989). All items are prefaced with “As a result of my/my partner’s illness...” and example demands include “I go out with friends less often”, “I feel he/she is less attractive”, and “Our family income has gone down”. Internal reliability coefficients for total DOI scale are 0.97 for both mothers’ and fathers’ measures.

**Parenting Quality** for both the mother and father was measured by the Inventory of Parent and Peer Attachment (IPPA) which assesses adolescents’ perceptions of their relationship with their parents and friends. It has 3 scales, including attachment levels to their mother, father and peers. Only the 2 scales regarding attachment to parents were used for purposes of the current study. Questions regarding attachment to the mother include, “My mother respects my feelings,” and “My mother can tell when I am upset about something.” Answers are based on a 5 point interval scale ranging from “Almost Never True” to “Almost Always True.” The same questions are asked about attachment with the father. Internal reliability coefficients were .92 for the attachment to mother scale and .96 for the attachment to father scale for the study sample.

**Adolescent Functioning** or child behavioral-emotional adjustment was measured by the Child Behavioral Checklist Scale (CBCL). The CBCL measures behavioral problems and social competencies. Total CBCL as well as 2 subscales, Internalizing Problems and Externalizing Problems were used in the current study. The Internalizing Problems subscale assesses behavior characterized as fearful, inhibited and over-controlled. The Externalizing Problems subscale measures behavior which is overly aggressive, antisocial and not under control. CBCL scores are standardized based on age and gender of adolescent and reported values are t-scores.

**Adolescent Competence** was measured by the Rosenberg Self-Esteem scale. This 10-item scale assesses the self-appraisal component of self-esteem by adolescent self-report. Response options use a 4-point Likert scale, with options of “Strongly agree” to “Strongly disagree.” Example items include “I feel I have a number of good qualities”, and “I wish I could have more respect for myself.” The internal reliability coefficient for this scale is .86 for the study sample.

In addition to the theoretical predictive variables, 14 treatment, demographic, and medical related variables were measured for use in testing the model of adolescent adjustment. Demographic variables that were examined included age of mother, father and adolescent; gender of adolescent; length of marriage; years of education of both mother and father; ethnicity of both parents; and total family income. Treatment and medical related variables included: type of surgery (lumpectomy or nodal dissection versus partial or radical mastectomy); radiation or chemotherapy treatment in the recent 3 months prior to obtaining the baseline data; number of reported side effects; and the mother’s use of medications for managing symptoms or side effects.

### **Data preparation**

There were 4 phases to data analyses: preparatory, tests of the full theoretical model, tests of the reduced model, and tests of the fit of the model. Each phase will be briefly described next.

Prior to model testing, the distributions of the study measures were inspected for normalcy, need for data transformation, collinearity in the predictors; and to assess presence of outliers. Distributions approximated the normal distribution and no data transformations were needed. There was no evidence of collinearity in the univariate or bivariate case. One CES-D score obtained from a mother was high comparatively, for the data set. However analyses done both with and without this data point showed no difference in outcomes.

Tests of the full theoretical model were based on multiple regression analyses. Regression models were run for mothers' and fathers' data separately. Predictors for each dependent concept in the theoretical model were simultaneously entered in a block entry. Initially the full theoretical model was tested. The criterion used to retain paths was set at  $p < .10$ , and all paths that met this criterion were retained from the full model for estimating the reduced model.

Tests of the reduced model involved re-estimating the regression models using only the retained paths, and re-estimating the standardized betas. Paths that met a criterion of  $p < .05$  were significant and are reported as Reduced Models in Figures 2 and 3, for mothers' and fathers' data, respectively.

Finally tests of the model fit were run for both the mother's data and the fathers' data separately, regressing each variable with all possible prior predictors. This method allows the testing of the paths that were hypothesized to be zero pathways in the full theoretical model.

## **Results**

### **Description of Study Measures for Study Sample**

**Depressed Mood** The mean CES-D depression score for mothers was 11.4 (SD 8.7), with 23 (31%) having a CES-D greater than or equal to 16, a known clinical cut off point for depression. The fathers' depression scores were slightly lower than the mothers' scores with a mean of 9.1 (SD 7.9). Only 12 fathers (16.2%) had a CES-D greater than or equal to 16. See Table 1 for a complete summary of study measures including theoretical ranges on scores and the alpha internal consistency reliability coefficients calculated for the current study sample.

**Spanier Dyadic Adjustment Scale** Of the 74 mothers, 10 (13.5%) had a Spanier DAS score less than or equal to 100, with a mean DAS of 115.6 (SD 14). The spouses' DAS scores were almost equivalent to the scores of their wives with a mean of 115.1 (SD 12.8). Nine fathers (12.2%) had a score less than or equal to 100.

**Demands of Illness** scores for the mothers averaged 157.6 (SD 69.4) at baseline. Demands of Illness scores for the fathers averaged 108.1 (SD 60.1).

**Parenting Quality** on the mothers' parenting scale (IPPA) had a mean of 100.1 (SD 14.7) at baseline with a theoretical range of 25-125. The quality of the fathers' parenting scale (IPPA) had a mean of 91.0 (SD 20.1) with a theoretical range of 24-120.



**Adolescent Competence** was measured by the Rosenberg Self-Esteem scale. The total scale score averaged 16.4 (SD 4.2) with a theoretical range of 10-40. Higher values on the Self-Esteem scale indicate lower self esteem.

**Adolescent Functioning** on the total scale of the CBCL was 48.1 (SD 12.1), with a mean Internalizing subscale of 50.2 (SD 11.1) and Externalizing subscale of 48.8 (SD 10.2).

### **KEY RESEARCH ACCOMPLISHMENTS**

All of activities in the Statement of Work have been completed. However, I requested a 1-year extension in order to protect the funds that were in the budget to attend the Era of Hope Conference in 2008.

We are currently in the process of writing publications for the professional journals. In addition, results from the current study will be used as a central part in designing an educational counseling intervention for adolescents and their diagnosed mothers with non-metastatic breast cancer.

#### **Statement of Work**

***Completed Task 1.*** Raw data file clean up (Months 01-02)

- a. Examination of distributions of all study variables for each of 339 study participants. Includes background, treatment, and standardized questionnaire data
- b. Examination of outliers in both univariate and bivariate cases on all study participants

***Completed Task 2.*** File preparation for data analysis (Months 03-04)

- a. Examination of completion rates for each study participant on each study variable
- b. Examination of sampling distributions for each study variable for adolescents and diagnosed patients
- c. Imputation of missing data as needed
- d. Data transformation as needed
- e. Calculation of internal consistency reliability for each standardized scale and subscale for study sample

***Completed Task 3.*** Data analyses for tests of study hypotheses (Months 05-08)

- a. Identification of potential covariates for theoretical model for both adolescents and diagnosed patients
- b. Creation of syntax statements for creating separate path analysis models for separate indicators of adolescent functioning
- c. Calculation of path models for tests of study hypotheses:
  - 1) Tests of the theoretical model
  - 2) Estimation of direct and indirect paths for theoretical model
  - 3) Tests of the fitted models
  - 4) Discriminant function analysis and calculation of classification accuracy in predicting poorly adjusted adolescents

***In Progress: Task 4.*** Report writing, publications, and dissemination (Months 09-12)

- a. Submission of technical paper to professional journal that summarizes the significant factors affecting adolescent adjustment.

This Task 4a is almost completed.

- b. Final report to Department of Defense.

I am submitting an Annual Report; this grant was awarded a 1-year extension.

- c. Development of intervention for adolescences or adolescent-parent dyads to enhance adolescent adjustment to maternal breast cancer

Task 4c is being developed now, based on current study results. I will be writing at least 1 grant to fund a pilot study of the proposed multi-component educational counseling intervention that will involve adolescents as well as the diagnosed mother with breast cancer.

## **REPORTABLE OUTCOMES**

### **Results from Tests of the Theoretical Model**

Prior to computing the regression coefficients, the relationships were examined between demographic and treatment variables and Demands of Illness and Parent Mood. Mothers who were receiving medications to manage side effects scored higher on the total scale of the Demands of Illness Inventory ( $p=.01$ ). A lengthier diagnosis also contributed to a greater number of reported illness-related demands ( $p<.05$ ). In addition, a lengthier diagnosis and a greater number of reported side effects from medications significantly affected depressed mood.

There were no significant relationships between demographic characteristics and depressed mood, with one exception. Education was significantly related to depression; was higher in less well educated mothers.

Results from the Reduced Model are summarized in Figures 2 and 3 for diagnosed mothers and fathers, respectively. Standardized beta coefficients and p-values are reported for each path. Results from data obtained from mothers and adolescents are presented first, followed by results obtained from fathers and adolescents. See Table 2 for results from the Reduced Models for both diagnosed mothers and fathers.

**Figure 2 Results from Mothers:** The final Reduced Model for mothers' data showed that greater demands of illness on the diagnosed mother increased her depressed mood ( $\text{Beta}=.57, p<.001$ ), which in turn decreased her marital adjustment ( $\text{Beta}=-.27, p<.001$ ). However, the mother's marital adjustment did not subsequently affect the adolescent's competence (self-esteem). Maternal depressed mood tended to negatively impact on adolescent competence; recall that higher scores denote lower self-esteem and less competence); ( $\text{Beta} = -0.20, p=.055$ ). Higher parenting quality predicted better self-esteem ( $\text{Beta} = -.47, p<.001$ ) as well as adolescent functioning on both the total CBCL score and the Externalizing Problems subscale (Externalizing CBCL  $\text{Beta} = .31, p<.05$ , Total CBCL  $\text{Beta} = -.26, p<.05$ ).

**Figure 3 Results from Fathers:** The final Reduced Model for fathers' data showed that greater demands of illness on the father increased their depressed mood ( $\text{Beta} = .68, p<.001$ ).

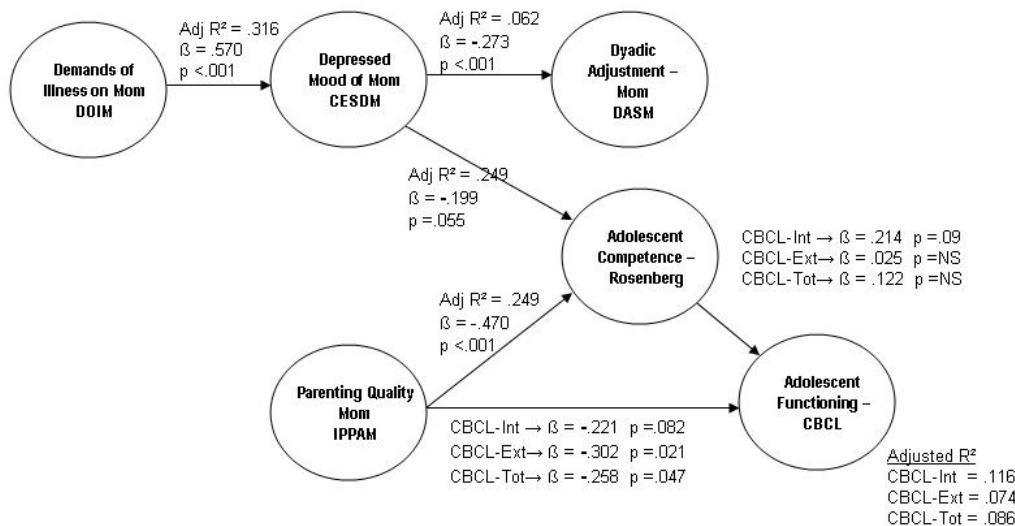
Increased depressed mood also predicted lower marital adjustment (Beta = -.43,  $p < .001$ ). In contrast to results obtained from mothers, the fathers' view of their marital adjustment significantly predicted lower adolescent competence (Beta = .26,  $p = .01$ ). Better parenting quality by the father, as reported by the adolescent, predicted better self-esteem (lower score on Rosenberg, Beta = -.52,  $p < .001$ ). Finally, parenting quality and adolescent competence predicted separate aspects of the adolescents' functioning. The Rosenberg Self-Esteem scale predicted lower Internalizing Problem scores on the CBCL (Beta = .29,  $p < .05$ ), and fathers' parenting quality predicted less Externalizing Problems (Beta = -.26,  $p = .05$ ).

### Tests of Fit of Model

The test of model fit was calculated by running regression models of all the variables in the initial theoretical model {Figure 1) with all the plausible predictors, including those paths that were hypothesized to be zero in the original theoretical model. All tests of the zero order paths were non-significant, indicating that the initial theoretical model was not misspecified.

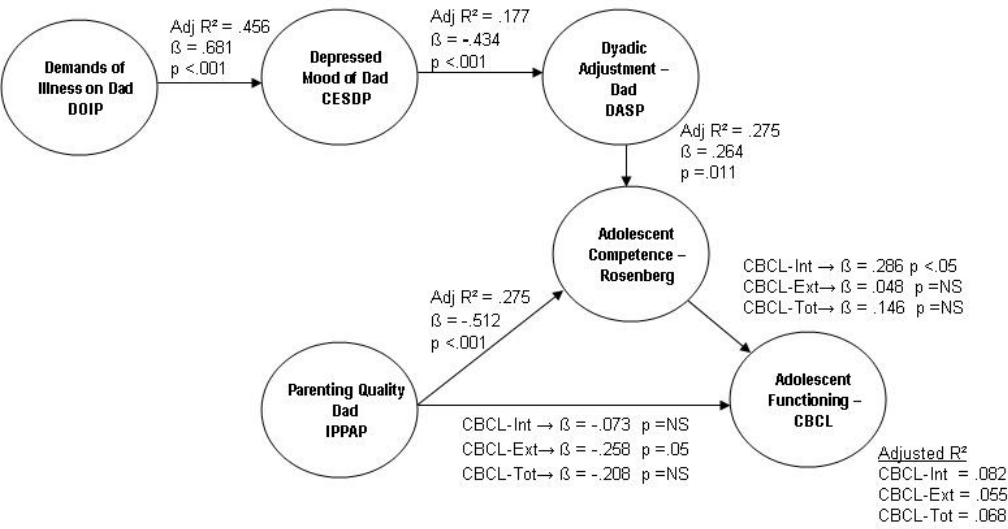
**Figure 2: Reduced Model for Mothers' Data**

Reduced Model – Mother's Data



**Figure 3: Reduced Model for Fathers' Data**

**Reduced Model – Dad's scales**



**Table 1: Description of Study Measures for Study Sample**

<b>Scales</b>	<b>Mean</b>	<b>Median</b>	<b>Std Deviation</b>	<b>Sample Minimum</b>	<b>Sample Maximum</b>	<b>Theoretical Range</b>	<b>Reliabilities</b>
<b>Mother's Measures</b>							
CES-D TOTAL	11.41	10.00	8.67	0	50	0-60	0.88
SPANIER TOTAL	115.58	117.50	14.00	74	141	0-145	0.92
DOI PHYSICAL SYMPTOMS	13.78	12.00	8.75	0	39	0-48	0.83
DOI PERSONAL MEANING	31.95	29.00	14.34	7	63	0-64	0.93
DOI FAMILY FUNCTIONING	42.71	41.00	21.88	9	105	0-140	0.92
DOI SOCIAL RELATIONS	13.05	11.50	8.31	0	36	0-40	0.86
DOI SELF-IMAGE	12.38	12.00	8.47	0	34	0-36	0.87
DOI MONITOR SYMPTOMS	17.73	16.50	10.77	2	43	0-44	0.94
DOI TREATMENT ISSUES	26.98	26.00	14.92	0	84	0-128	0.88
DOI TOTAL OCC1	157.62	139.22	69.53	49	370	0-500	0.97
<b>Father's Measures</b>							
CES-D TOTAL	9.12	7.50	7.86	0	37	0-60	0.87
SPANIER TOTAL	115.12	115.50	12.81	78	137	0-145	0.91
DOI PHYSICAL SYMPTOMS	4.39	2.00	6.35	0	37	0-48	0.91
DOI PERSONAL MEANING	22.04	19.50	12.67	0	64	0-64	0.92
DOI FAMILY FUNCTIONING	38.16	35.00	21.77	4	114	0-140	0.94
DOI SOCIAL RELATIONS	7.74	6.00	6.84	0	32	0-40	0.87
DOI SELF-IMAGE	3.65	3.50	3.33	0	15	0-36	0.74
DOI MONITOR SYMPTOMS	12.14	10.50	7.76	0	31	0-44	0.89
DOI TREATMENT ISSUES	19.95	17.50	12.98	2	62	0-128	0.88
DOI TOTAL	108.07	95.00	60.13	12	299	0-500	0.97
<b>Adolescent's Scales</b>							
MOTHER RELATIONS (IPPA)	100.07	101.00	14.68	68	125	25-125	0.92
FATHER RELATIONS (IPPA)	91.01	93.00	20.10	36	125	24-120	0.96
FRIEND RELATIONS (IPPS)	99.80	104.50	12.70	61	120	25-125	0.92
ROSENBERG	16.34	16.00	4.20	10	25	10-40	0.86
CBCL Total Behavioral Problems T-score	48.07	44.50	12.11	23	75	0-100	
CBCL Internalizing Problems T-score	50.22	50.00	11.12	31	76	0-100	
CBCL Externalizing Problems T-score	48.78	47.00	10.15	32	74	0-100	

**Table 2: Results from Tests of Reduced Models, Mother & Father-reported Data**

Dependent Variable		F	df	Multiple R	Adjusted R-square
Depressed Mood	Father	62.14***	1,72	0.681	0.456
	Mother	34.73 ***	1,72	0.579	0.316
Dyadic Adjustment	Father	16.74***	1,72	0.434	0.177
	Mother	5.79*	1,72	0.273	0.062
Adolescent Competence	Father	14.82***	2,71	0.543	0.275
	Mother	13.08***	2,71	0.519	0.249
Adolescent Functioning – Internalizing	Father	4.25*	2,71	0.327	0.082
	Mother	5.81**	2,71	0.375	0.116

\*p < .05, \*\*p<.01, \*\*\*p<.001

### **CONCLUSION**

This Concept Award enabled the study team to test a theoretical predictive model of adolescents' functioning with recently diagnosed, non-metastatic maternal breast cancer using multivariate statistics and multiple measures from two-parent households and adolescents. Data from the adolescents' fathers were analyzed separately from data obtained from the adolescents' diagnosed mothers. Based on study results, the study team is currently developing a multi-component, multi-method educational counseling intervention for adolescents impacted by newly diagnosed breast cancer in their mother. This intervention will include face to face sessions between a specially trained patient educator and the adolescent as well as face to face sessions between the diagnosed mother and the specially trained patient educator. Printed material will be developed for the non-ill parent, guiding ways to support the adolescent about the mother's breast cancer. The proposed intervention will be designed to directly enhance the adolescent's positive self-appraisal (self-esteem), the quality of parenting from both the ill mother and the non-ill father, and to diminish depressed mood in the ill mother that is attributed to the cancer.

Results obtained from both fathers' and mothers' data in this completed study highlight the critically important nature of parenting quality for adolescents impacted by maternal breast cancer. Even as adolescents are individuating and increasing in their autonomy and self-identity, current study results reveal that maternal mood and parenting quality from both parents are significant sources of positive influence on the adolescent's self-esteem and their behavioral-emotional functioning. It would be totally inappropriate, based on current study results, to suggest that adolescents can be left on their own during the acute period of diagnosis, treatment, and medical management of their mother's breast cancer. Quite the contrary, adolescents significantly benefit from parenting from both the ill and non-ill parent.

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